



# **IDENTIFYING AND OVERCOMING THE CHALLENGES OF PROFESSIONAL AND FAMILY COLLABORATIONS IN CAREGIVING**

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## MY RESEARCH QUESTION

“How do the support networks of community dwelling rural elders with physical limitations evolve in richness and complexity over time?”



# OVERALL APPROACH

- Phase One (Rural Elders)
- Phase Two (Support Network Members)
- Phase Three (Home- and Community-based Service Providers)



# RESEARCH LOCATION

Three rural counties in Appalachian North Carolina

- County Population density ranged from fewer than 60 to as many as 70 people per square mile (U.S. Census, 2008)
- Mountainous terrain
- No urban centers in any of the counties
- Higher than average older adult population:
- Between 17% and 19% of each county's population is over the age of 65 (NC and US 12%)

(U.S. Census, 2008)



# PARTICIPANTS

## **Rural Elders**

Gender: 9 women and 7 men

Age range: 66 to 90

Marital status: 10 were widowed, 3 were married, 2 never married, 1 divorced

Living arrangements: 7 lived with family, 9 lived alone (3 with family on same property)

Health status: Very good: 2 Good: 2 Fair: 5 Poor: 3 No response: 4

All had physical limitations

All Caucasian

Caregiving responsibilities

## **Support Network Members**

1 wife, 3 daughters, 1 son, 2 neighbors and 1 paid helper

## **Formal Service Providers (6 agency administrators)**

Agency Type:

3 Senior Centers

3 Medicaid Waiver Agencies

Agency Administration:

2 County government

2 State government

2 Private non-profit



# **FORMAL SERVICE PROVIDERS' INTERVIEW GUIDE**

What are the advantages, challenges and barriers to working with family members and other helpers in the assessment, planning, and implementation of services?



# **FINDING: SINGLE NETWORK WITH DIFFERENT RULES**

Rules and norms governing communication  
differ

Formal network members:

- Require written releases to talk with anyone

- Connect with one or two family members

Informal network members:

- Information flows freely

- Communication is needed in order to coordinate assistance



## **MRS. FELLOWS, AGENCY STAFF MEMBER:**

It just seemed like she had family coming out of the woodwork, especially when there was a problem, people I never heard of callin' me. They wanted to discuss everything and they wanted me to discuss everything with them because, you know, I told them that I have a contact person and that's the person that I can talk to about issues, you know, and that person was this person's son but, you know, this was distant relatives like cousins and sister-in-laws and all of this and you know I finally had to say, 'I'm sorry. I can only talk to the contact person.' Because I was havin' all these family members and everybody thought something different. They wanted me to do something different. And I was like, 'I'm sorry I can not please all of you.'



## **RECOMMENDATIONS:**

**Have multiple contacts that include informal supporters who are actively involved in the network**

**Using team approach that includes multiple network members may be more effective than a single individual that channels between the formal and informal parts of the network**



# **RULES AND NORMS GOVERNING FUNCTIONS DIFFER**

## **Formal network members:**

- Limited by functions assessed as necessary

- Limited by training and regulations

- Transportation and medication management

## **Informal network members:**

- Limited by ability and availability

- Do what needs to be done



## **RECOMMENDATIONS:**

Efforts should be made to align agency rules with the rules and norms of the rest of the network

Provide more flexibility with regulations

Serve the network as a whole rather than just the individual





# **FINDING: INTIMACY DEVELOPS BETWEEN RURAL ELDERS AND THEIR PAID CAREGIVERS**

Intimacy with paid helpers stems from emotional connections

The development of intimacy by participants towards paid helpers can come from spending time together



## **RECOMMENDATIONS:**

Professional boundaries are not always realistic

Strategies are needed for dealing with the emotional challenges of service termination for both the client and the provider

Future research should explore intimacy development between care recipients and formal care providers



# NEXT STEPS

- Replicate and expand the study to include
  - Providers of direct service instead of just administrators
  - Administrators in more densely populated areas
  - More older adults
  - More members of their informal networks
- Regulator changes, training and support for agencies regarding these challenges







**FOR COPIES OF THESE SLIDES CONTACT  
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